
National AIDS Hotline: HIV and AIDS Information Service Through a Toll-Free Telephone System

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Synopsis

The National AIDS Hotline (NAH), a service of the Centers for Disease Control (CDC), is an information resource for the population of the United States, its Territories, and Puerto Rico concerning the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). Since its inception in 1983, NAH has grown to be the world's largest health-related

hotline service. NAH has received an average of more than 1.4 million calls per year since October 1987. Services of NAH include responding to the public's questions about HIV and AIDS and providing referrals to State and local resources. All services, including HIV and AIDS publications, are provided free of charge.

The public contacts NAH 24 hours a day, 7 days a week, through a toll-free telephone system. Services are available to English-speaking, Spanish-speaking, and deaf populations. Each service has its own telephone number—English-speaking, 1-800-342-2437; Spanish-speaking, 1-800-344-7432; TTY service for the deaf, 1-800-243-7889.

NAH employs approximately 170 information specialists to answer calls. The facility uses modern telecommunications technology to effectively manage and direct calls to 43 work stations. Each work station is supported by a personal computer that allows access to CDC's National AIDS Clearing-house data bases for referrals and publication ordering. NAH ensures that information provided to the public is current, accurate, and consistent with approved government policy. Quality assurance reviews address call management, delivery of information, and content of calls.

DEMAND FOR INFORMATION about human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) has been, and continues to be, greater than that for any other health problem. Since 1983, the National AIDS Hotline (NAH) has been a primary information and referral service for the American public, providing current facts non-judgmentally, confidentially, and sensitively.

The CDC hotline service occupies a key role in HIV and AIDS prevention by providing information about how HIV infection is spread and how its transmission can be prevented. In addition, NAH reduces callers' fears by giving information on how HIV is *not* transmitted. Given that a cure for HIV infection and AIDS is not currently available, dissemination of prevention information to the public for the purpose of changing attitudes and behaviors is an important tool in controlling the disease.

A "key to changing attitudes and behaviors is the provision of factual, consistent, and under-

standable information about HIV and AIDS by persons and organizations in whom the recipient has confidence," according to the "Public Health Service (PHS) Information/Education Plan to Prevent and Control AIDS in the United States" (1). The plan goes on—"PHS has a responsibility to provide clear and accurate information about acquired immunodeficiency syndrome (AIDS) to all segments of our society." Lead responsibility for that role was given to CDC in 1986.

Hotlines are being used successfully by health communication programs as a way to disseminate information to the public. Rosenbaum and Calhoun (2) cite several reasons for this success.

- The caller has more control over the situation.
- The caller can remain anonymous if he or she chooses.
- Hotlines break geographic barriers.
- The operator can also remain anonymous.

Anonymity seems especially important when dealing with the delicate subject matter of HIV infection and AIDS. Wark states, "Anonymity seems to enable the caller to take larger risks in the expression of painful feelings more quickly than in the face-to-face setting" (3).

The real worth of the NAH is ultimately judged by the public—how well does this service meet the personal needs of callers—callers who have dialed the Hotline for myriad reasons, callers such as the worried well, the HIV positive person, the person living with AIDS, the physician needing information for a patient, the angry citizen, the person in pain and despair, and so forth.

Memorable calls, as related by hotline information specialists, illustrate the scope of service they provide:

- "The nature of our [NAH] service often involves callers who are already infected or fearful that they have been. It is good to have the chance to speak to someone about prevention before the fact. One such call I took was from a young man wanting to know how to avoid AIDS. His obvious hesitancy, as he spoke about sex and condoms with a stranger on the telephone, was at first a hindrance to the call development. However, he was determined and did not want to stop until he was certain of the facts.

"We talked through information on risks and safeguards relating to sexual practices, abstinence, and facts about the virus as well. He asked many questions which led us to cover an incredible range of topics. As need for in-depth information was sated, the call was ended, and the last words I heard from him were, 'Love you.' "

- "An elderly woman called because she needed some help. Her 24-year-old, bedridden daughter, who was dying of AIDS, had come home with her four children. The woman was the sole caretaker for her daughter and the grandchildren. As if these were not enough pressures, the daughter was taking her fear, anger, and frustration about dying out on the only one close, her mother. The rages had become increasingly frequent and intense as the young woman's illness progressed. The mother had been abandoned by most of her family and friends, and even her minister found excuses not to visit.

"This elderly woman was so grateful for referrals I was able to supply for counseling and support groups in her nearest town (30 miles away). She repeated over and over, 'I love my child, I'll be there until her last breath, I love my

child. I just need some help to get through it all.' The elderly woman ended the call by saying, 'God bless you, God bless you.' "

- "A lady called to try to find information for her neighbor who has AIDS. She was not worried, as so many are, about being around him or contracting the virus. She wanted to find homecare help for him, as she knew he would need assistance. She was well aware of the prejudices he would face from other neighbors. The referrals she needed were simple and straightforward. This woman's concern for a fellow human being reminded me strongly that people do still care."

These calls vividly illustrate the American public's thirst for information that will help them understand AIDS and how it can (and cannot) be transmitted, for consolation and reassurance for those living with the disease, and for appropriate referrals to services that help people cope with the threat of HIV infection and AIDS. In meeting these needs, the NAH has become a stable and recognized source of information for millions of Americans. Some key events that have had an impact on its development are described in the box, page 630.

Present Operations

Basic hotline services include discussing information about HIV infection and AIDS, making referrals to State and local services, and filling orders for HIV and AIDS publications. According to the "National AIDS Hotline Annual Report 1989" (5) NAH supplied callers with more than 330,000 referrals to State and local HIV and AIDS services and filled nearly 1.2 million publications orders that year. Following stabilization of NAH's capacity to handle calls, call volumes rose in a consistent pattern from 1987 to the present (see box and tables 1 and 2), with the exception of a noticeable spike in volume around the national mailout in June 1988. At present, volume averages almost 3,300 live calls daily.

In addition to the three basic services, NAH serves as a "hotline for other hotlines." It advises State and local organizations regarding operation of their hotline services and provides them with suggested responses to questions generated by new, scientific advances, as well as information about government policy on HIV and AIDS issues. CDC scientists and other recognized expert resources provide the information used and disseminated by NAH.

Chronology of Key Events Related to the National AIDS Hotline (NAH)

February 1983—NAH established and operated by Federal Government (HHS, PHS, Office of Public Affairs).

July 1983—NAH services expanded to 24 hours a day, 7 days a week; toll-free lines were implemented, and the number 1-800-342-AIDS was assigned to the Hotline (4).

March 1985—NAH transferred to CDC in Atlanta, GA, from Washington, DC. •

July-August 1985—Media coverage of Rock Hudson's illness increases call volume significantly.

September 1986—Contract awarded to American Social Health Association for operation of NAH.

December 1986—HIV-AIDS information services began in Palo Alto, CA, with 7 incoming telephone lines.

February 1987—NAH services transferred to New York City; referral data bases implemented.

October 1987—National AIDS Clearinghouse established, and electronic linkage made to computerized referral data bases and a publications ordering system.

October 1987—NAH services transferred to Research Triangle Park, NC.

May 1988—Spanish-language services added to respond to calls generated by the national mailout of "Understanding AIDS."

June 1988—National mailout of "Understanding AIDS."

August 1988—Full-time Spanish-language services implemented (1-800-344-7432, 7 days a week, 8 a.m. until 2 a.m. eastern time, with a taped message during hours when information specialists are not available).

September 1988—TTY services for the deaf began (1-800-243-7889 (TTY), Monday through Friday, 10 a.m. to 10 p.m. eastern time), with a recorded message for callers during hours when information specialists are not available).

March 1989—All NAH operations and equipment moved to Research Triangle Park; New York City services terminated.

February 1991—Cumulative calls received reach 5 million.

accepts referral calls from hotlines that do not have Spanish and deaf specialty services.

Call Content

As the public's knowledge of HIV and AIDS has increased, the type and scope of questions have changed. In contrast to general questions received during the mid-to-late 1980s—such as "What is AIDS?" and "How do I get it?"—callers now ask more specific questions. For example, questions address the incubation period of HIV, types of testing procedures used to identify HIV antibodies, reliability of testing procedures, statistical information regarding methods of transmission, and the difference between confidential and anonymous testing.

As the questions have become more complex, the length of telephone calls has increased. NAH calls lasted approximately 3 minutes during the mid-to-late 1980s. In contrast, the "National AIDS Hotline Monthly Report, October 1990" showed the average length of call for the English-speaking population to be 6.5 minutes (6). Increases have also been observed for Spanish and deaf services. The Spanish-speaking service calls last an average of 16 minutes, and the deaf population calls average 20 minutes.

According to the October report, the number one initial concern of callers was transmission (37 percent). This issue was followed, in order, by testing questions (18 percent), requests for written materials (15 percent), and questions about the course of HIV infection and AIDS (13 percent).

The NAH referral service has grown substantially since an electronic linkage was established between the Hotline and the National AIDS Clearinghouse (NAC). The figure shows the percentage distribution of referrals for fiscal year 1990, when 299,441 referrals were made. Callers who require reference services are referred to the Clearinghouse, and callers needing information about AIDS clinical trials are referred to the AIDS Clinical Trials Information Service.

Promotion of NAH Services

The "America Responds to AIDS" (ARTA) public service advertising campaign was launched in October 1987. ARTA contributes significantly to the promotion of NAH services. Print, voice, and audiovisual materials provided by ARTA identify the NAH telephone numbers and services to the public.

NAH provides backup services for State and local HIV and AIDS hotlines, which do not operate 24 hours per day or 7 days per week and

In addition to ARTA efforts, public and private organizations promote NAH to their constituents. Major mass media resources present public service announcements about NAH. Examples of promotional efforts have been the "AIDS Quarterly," presented by the Public Broadcasting System, and numerous HIV and AIDS public service announcements produced and presented by CBS and NBC television. Publications such as *Parents and Parade* magazines have published the NAH telephone numbers, as have a number of school health textbooks. The numbers have been publicized by television personality Geraldo Rivera and were included on package inserts with music recordings by Madonna and other recording artists.

The NAH actively promotes its services to the public. Approaches used include participation in HIV and AIDS workshops and exhibits at conferences and health fairs. During January through October 1990, NAH provided exhibits at 25 national and international conferences.

NAH Resources

There has been a significant increase in the number of personnel required to deliver NAH services since 1983. At present, the number of information specialists employed averages 170. Experience has shown that shifts ranging from 4 to 6 hours are most effective because of the intensity of the work. Information specialists work an average of 20 hours per week. There are no volunteer information specialists. The 43 incoming telephone lines allow for 35 English-language, 5 Spanish-language, and 3 deaf population work stations to be staffed.

When call volume dictates flexibility, NAH can redistribute work station usage to accommodate unusually high demand from one of the service populations. Each work station contains a personal computer for accessing the local area network, which allows users to share information, access the AIDS Information Package (AIP), and connect with the referral data base of NAC. Work stations providing TTY service are also equipped with a TTY-TDD machine to allow two-way communication with deaf callers.

The AIP is used to collect information about the requests and needs of callers. Among other uses, this information helps evaluate the training needs of information specialists and determine effects of media exposure on call volume. Information specialists log various types of information about incoming calls, including questions raised, referrals

Table 1. Cumulative telephone calls to the National AIDS Hotline since contractor services began, January 1987–March 1991

Month and year	Calls	Month and year	Calls
1987		1989	
Jan.....	0	Jan.....	2,886,138
Feb.....	6,714	Feb.....	2,972,750
Mar.....	70,424	Mar.....	3,068,416
Apr.....	126,001	Apr.....	3,169,976
May.....	192,997	May.....	3,273,505
June.....	269,487	June.....	3,385,588
July.....	341,975	July.....	3,495,031
Aug.....	413,650	Aug.....	3,598,488
Sept.....	487,955	Sept.....	3,679,007
Oct.....	645,714	Oct.....	3,750,396
Nov.....	838,746	Nov.....	3,823,267
Dec.....	1,041,563	Dec.....	3,901,079
1988		1990	
Jan.....	1,242,784	Jan.....	3,993,921
Feb.....	1,417,141	Feb.....	4,073,558
Mar.....	1,614,344	Mar.....	4,153,341
Apr.....	1,795,656	Apr.....	4,240,728
May.....	1,979,406	May.....	4,328,202
June.....	2,191,145	June.....	4,410,406
July.....	2,316,918	July.....	4,491,252
Aug.....	2,418,618	Aug.....	4,568,789
Sept.....	2,509,349	Sept.....	4,635,954
Oct.....	2,600,339	Oct.....	4,703,958
Nov.....	2,686,740	Nov.....	4,759,635
Dec.....	2,772,757	Dec.....	4,855,146
		1991	
		Jan.....	4,960,844
		Feb.....	5,056,484
		Mar.....	5,157,691

made, and requests for literature. The package is a "passive" data collection system. Information is not directly solicited from callers; rather, information is recorded as a result of discussions taking place during the call. AIP does not include the callers' names or other personal identifiers, so confidentiality is assured.

The referral data base system used by NAH is developed and maintained by the Clearinghouse. The NAH information specialists use information in the data base to refer callers to State and local HIV-AIDS services.

Handling the volume of calls to NAH is facilitated by an automatic call distribution device at NAH that routinely directs incoming calls to staffed work stations. The call management information provided by this device enables NAH to determine its staffing needs and to evaluate staff efficiency.

Major emphasis is placed on quality of services. Various activities throughout NAH are monitored, including technology, the content and methods of

Table 2. Volume of live telephone calls to the National AIDS Hotline since contractor services began, February 1987–March 1991

Month and year	Calls	Month and year	Calls
1987		1989	
Feb.	6,714	Jan.	113,381
Mar.	19,380	Feb.	86,612
Apr.	17,697	Mar.	95,666
May	17,466	Apr.	101,560
June	19,300	May	103,529
July	21,678	June	112,083
Aug.	23,155	July	109,443
Sept.	20,497	Aug.	103,457
Oct.	49,594	Sept.	80,519
Nov.	67,332	Oct.	71,389
Dec.	69,378	Nov.	72,891
		Dec.	77,812
1988		1990	
Jan.	70,148	Jan.	88,784
Feb.	65,493	Feb.	79,637
Mar.	73,198	Mar.	79,783
Apr.	68,604	Apr.	87,387
May	124,078	May	87,474
June	211,849	June	82,204
July	107,773	July	80,804
Aug.	101,700	Aug.	77,537
Sept.	90,731	Sept.	67,165
Oct.	90,990	Oct.	68,004
Nov.	86,401	Nov.	79,297
Dec.	86,017	Dec.	95,511
		1991	
		Jan.	105,698
		Feb.	95,640
		Mar.	101,207

training programs, and individual performance. Both internal and external systems of quality control are used.

Personnel

NAH recruiting criteria are designed to find the best qualified information specialists. Candidates must be able to deal maturely with HIV–AIDS subject matter and must possess good interpersonal and communication skills. They must also be able to present information objectively without making medical or value judgments and respond to callers in a sensitive and caring manner while avoiding a counseling role.

Candidates for the Spanish-speaking service, in addition to being bilingual, must possess knowledge of the differences among Hispanic cultures. The deaf service requires that employees be either deaf or from families with deaf members and be thoroughly competent in American Sign Language, since the structure of this language influences the written communication of the deaf.

Each information specialist must successfully complete a 45-hour training program before being assigned to answer calls from the public. Examinations are given that determine the trainees' content knowledge for each of the training sessions. A comprehensive examination on AIDS information, technical systems, and communications skills is given at the completion of the course.

Supervisory personnel orient new information specialists to their work responsibilities. Information specialist trainees listen to supervisors answer calls, then discuss issues raised and responses given. Language modeling of callers is stressed in order that information will be understood by the caller. Upon successful completion of the orientation process, close and direct supervision is provided when the information specialist begins to accept calls from the public.

Calls are monitored by shift supervisors. As a minimum, call evaluation assessments address accuracy and consistency of information, courtesy, avoidance of medical and value judgments, clarity of information presented, appropriateness of referrals, and appropriateness of the information specialist's language level and style.

Information Development and Validation

To ensure that information about HIV and AIDS is timely, accurate, and consistent, CDC develops and reviews information and disseminates it to NAH. CDC, through the NAH Project Officer, evaluates information content, determines the timing for release of information, and develops policy statements to be used in response to news items about HIV and AIDS.

CDC assigns staff experts on an issue or topic to develop responses to potential questions. The review process often involves committee action to develop a CDC consensus on a position. When issues require the expertise and input of persons employed at other Public Health Service agencies (for example, National Institutes of Health, Food and Drug Administration), those agencies conduct reviews and make recommendations to CDC.

Inservice Training

Inservice training of information specialists and supervisory staff comprises a significant component of NAH quality assurance. Inservice presentations are made on a monthly basis, and attendance is mandatory.

The content of inservice training sessions is

determined by surveys of staff to identify their needs, receipt of new or updated HIV and AIDS information from the government, and identification of topics as a result of call monitoring exercises. A committee consisting of NAH administrators, supervisors, and training department personnel selects the topics.

Lessons Learned

Since February 1983, experience has led to a number of modifications in NAH operations. Although NAH has unique needs and functions because of its size and national scope, State and local hotlines may gain valuable information from NAH experiences. The NAH originally operated with volunteer staff to answer telephones; however, to maintain consistent information delivery, NAH now uses only paid staff.

Initially NAH did not offer 24-hour information specialist services, creating an access barrier for those unable to call during normal work hours. NAH has effectively eliminated this barrier by offering 24-hour service to the English-speaking population and extended hours for Spanish-speaking and deaf populations. By providing Spanish-language and TTY services, additional access barriers have been overcome, opening information services to an estimated 40 million additional U.S. citizens.

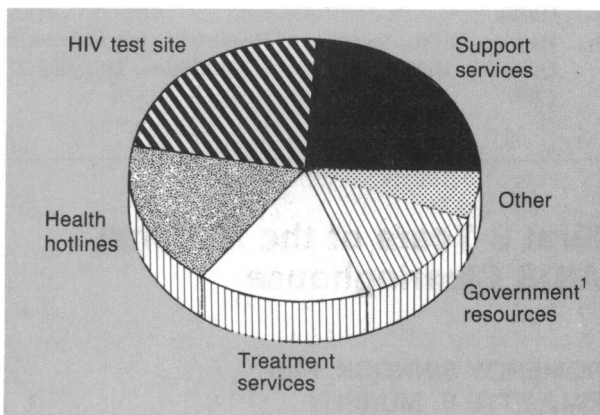
Evaluation of information specialist on-line performance was originally done through side-by-side observations. This approach proved inadequate because supervisors could hear only responses of information specialists. The tone of conversations, and questions being asked by callers, could not be heard. Call monitoring equipment now allows supervisors to hear both parties in a conversation, resulting in a far better ability to judge the performance of the information specialist.

Initially, information about calls was recorded and compiled by hand. The computerized AIDS Information Package now in use allows on-line data entry, saving time and providing higher reliability of information.

Conclusion

Telephone information systems such as NAH have become a critical channel for delivering health information to the public. These systems enable personalized service for those who choose to ask for information in an interpersonal interaction. When written materials are sent in response to

Percentage distribution of 299,441 referrals from the National AIDS Hotline, October 1989–September 1990



¹Centers for Disease Control, State HIV prevention coordinators, National AIDS Clearinghouse, AIDS Clinical Trials Information Service.

callers' requests, this guarantees a high probability of their being read. The telephone service is widely available, simple to use, and the "800" number adds accessibility.

It is generally accepted that simply providing information does not necessarily result in improved health practices, but it is an important step in prompting behavior change. Lessons learned so far in developing, implementing, and operating NAH lead to the belief that information is an important public health tool. The touching and memorable nature of calls, as well as the volume of calls, establishes the need that people have to reach out for more than just facts. It is important that those facts are delivered in a context of concern, sensitivity, confidentiality, and trust. This charge is central to NAH.

What is in store for the future? Some simple demographics will provide useful profiles for helping others reach target audiences. Insight into the content of calls, gathered confidentially, will provide valuable information about the questions that the public is asking. An understanding of where callers learn about the NAH will direct promotion efforts and can be used to assess the coverage of public service announcements. The future presents many challenges, but the heart of the matter is that the National AIDS Hotline is people helping people to combat HIV infection and AIDS.

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First 3 Years of the National AIDS Clearinghouse

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Synopsis

The National AIDS Clearinghouse is an information service provided by the Centers for Disease Control. The Clearinghouse was established in 1987 to respond to increasing numbers of public and pro-

fessional inquiries, to disseminate accurate information, and to make referrals to local sources of information and assistance. Four data bases—Resources and Services Database containing information about more than 16,000 organizations that provide counseling and testing for human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) and other education and prevention services; Educational Materials Database containing more than 8,000 individual, hard-to-find educational materials; Funding Database; and the AIDS Clinical Trial Information Service (ACTIS) Database—are searched by information specialists to respond to more than 45,000 requests annually for information from a variety of health professionals, organizations, and the general public.

Between 1987 and 1991, the Clearinghouse disseminated more than 60 million copies of publications related to HIV and AIDS. Information and education remain the most critical tools for the prevention of HIV infection, and the National AIDS Clearinghouse provides an essential element for the dissemination of education and prevention information.

SINCE THE FIRST REPORTS that documented the beginning of the human immunodeficiency virus (HIV) epidemic in 1981 (1,2), thousands of news stories and scientific articles about HIV and acquired immunodeficiency syndrome (AIDS) have been printed in newspapers, popular magazines, and journals and aired on radio and television.

Background

Although much has been learned about the virus, HIV infection, and the disease of AIDS as the epidemic has spread in the last 10 years, a gap remains between the growing body of HIV and AIDS information and what the public knows, understands, and believes (3). An even wider gap

exists between what is known about HIV infection and AIDS and the public's acting upon that knowledge to reduce or change behaviors that place persons at risk.

In the fall of 1986, the Centers for Disease Control (CDC) was assigned the lead responsibility in the Public Health Service (PHS) for informing and educating Americans about AIDS. Following the development of a comprehensive plan (4) in 1987, CDC established the National AIDS Information and Education Program and charged it with creating a national media campaign and an organized response to the public's interest, concerns, and needs generated by the campaign. The national media campaign brought together the tools of advertising and marketing to raise public awareness